

ADD Program Update

Administration on Developmental Disabilities

Administration for Children and Families • U.S. Department of Health and Human Services

Commissioner's Message

Welcome to Fiscal Year 2003. The first issue of "Update" for the Fiscal Year seems like the perfect time to discuss the goals for this year, together with the anticipated outcomes. Below are some of the many initiatives that I am excited about pursuing in the coming year.

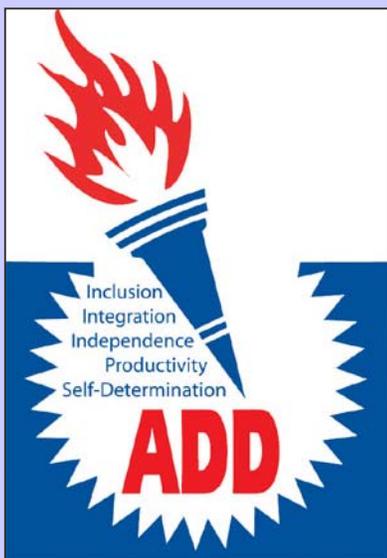
TANF-360 Initiative

In FY 2003 we anticipate finalizing our plan to tackle effective ways to help poor families, eligible for Temporary Assistance for Needy Families (TANF), who have a family member with a disability. This family member may be either a child or adult with a disability. Our goal is to take "a 360 degree look" at what these families need to be self-sufficient. We are exploring how to support "one-stop" demonstrations that would bring all appropriate agencies and supports to the planning process to help these families develop plans for self-sufficiency.

TANF families with a member who has a disability often need services and supports that cut across agency lines, such as those related to health and mental health, personal assistance, accessible transportation, accessible housing, job training, assistive technology, child care, and employment (with reasonable accommodations). These services and supports are available from a myriad of public and private providers, each of which has its own eligibility determination and planning process. Few States and communities have invested in a comprehensive infrastructure to offer these families a seamless, single point of entry to establish eligibility and develop a family-centered plan for self-sufficiency. Although there has been exploration of multi-agency collaboration among two to three agencies serving individuals with disabilities, the explicit or implicit lead has fallen to one agency to encourage others to serve individuals in need.

We anticipate providing competitive planning grants in 2003.

Planning grants would be awarded to partnerships of a state's governor, a locally elected official, and the developmental



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disabilities network. They would plan for setting up the one-stop in the home base of the local elected official.

The Administration on Developmental Disabilities and the Office for Family Assistance would jointly oversee the planning projects. We anticipate that many federal and state programs would contribute to the funding of family needs and technical assistance in later years through implementation grants.

Commissioner's Forum

Throughout the country, states, consumers, and providers of services are wrestling with two important issues: (1) the quality of services and supports provided to individuals with developmental disabilities; and (2) a shortage of qualified direct support professionals.

Quality Improvement means putting systems in place that will assist people with disabilities to be safe, healthy, and empowered to make choices about their lives. Quality improvement activities are undertaken by states to promote effective services that assure the health and welfare of individuals in home and community-based settings. Our goal is to balance consumer satisfaction, fiscal realities, human resources, regulatory compliance, and desired outcomes for people with disabilities.

ADD Commissioner's Forum will take place on Tuesday, February 18, through Thursday, February 20, 2003 at the Mayflower Hotel in Washington, D.C. The theme of the 2003 forum will be: Building a Comprehensive Quality Management Program and Supporting the Direct Support Workforce for DD Service Systems. In addition to members of the DD network, public and private partners will be invited to participate, including self-advocates and representatives from the U.S. Department of Labor, the Social Security Administration, Centers for Medicare and Medicaid Services, and the U.S. Department of Education (NIDRR). The U.S. Department of Housing and Urban Development has expressed interest in participating in the forum, and we look forward to their possible collaboration. Mark your calendars and make plans to attend this ground breaking meeting. The ADD Commissioner's Forum was developed collaboratively with the Developmental Disabilities Quality Coalition. The DD Quality Coalition is a confederation of national organizations that have banded together in a common effort to improve the quality and accessibility of community supports for children and adults with developmental disabilities. Members include: The Arc of the U.S.; the Association of University Centers on Disability; the American Association on Mental Retardation; the American Network of Community Options and Resources; the Council on Quality and Leadership; the Consortium of Developmental Disabilities Councils; the National Association of Protection and Advocacy Systems; the National Association of Developmental Disabilities Councils; and the National Alliance of Direct Support Professionals.

Some state programs will be showcased during the forum, demonstrating successful state-level, advocacy-sponsored, and/or provider-level initiatives that assure and improve the quality of community supports and/or enhance the competency and stability of the workforce serving individuals with developmental disabilities.

ADD's forum goals are to develop a strategic vision for person-centered quality management programs and innovative workforce initiatives. We are committed to learning the "recipes" of programs that work, recipes that equip you to try out new ideas when you return to your community and state. ADD will issue a summary report shortly after the forum. If you have any questions about the forum contact: Faith McCormick at ADD (202-401-6970), or Steve Eidelman, Executive Director, The Arc, at eidelman@thearc.org (301-565-5469)

Another initiative slated for the coming year is the Inclusive child care initiative. In FY04 expect to see increased focus on initiatives encouraging or supporting Adoption, Micro-business, special families and friends programs, and housing.

Program Progress

State Councils on Developmental Disabilities

Many states are currently experiencing budget deficits and financial shortcomings that will certainly have an effect on the provision of services and supports to people with developmental disabilities in the immediate and distant future. Through creative collaboration and coordination strategies, Councils can assist in easing the effects of budget deficits on the lives of people with developmental disabilities. Following are examples of Council projects that have leveraged the resources of other agencies and organizations to provide coordinated service delivery systems.

The Arkansas Dental Project addresses the lack of dental care for adults with developmental disabilities and coordinates different systems to provide dental services. The project is a collaborative effort between the Council, DDS, the Health Department, the Dental Association and other interested parties to identify needs and develop strategies to provide dental care.

A Denver, Colorado Council project on supported employment and transition works with young adults who have developmental disabilities and also are involved in or at risk for involvement with the criminal justice system. The project is part of a collaborative network of statewide partners, including the Division of Vocational Rehabilitation, the Colorado Department of Education, the Colorado Department of Labor, and Project WIN – a project funded by the Rehabilitation Services Administration and administered by the Colorado University for Excellence.

The Building Sustainable Business Partnerships of the Illinois Council is an innovative training curriculum using business marketing techniques for job seeker, job coaches, vocational service providers and advocates. As a result of this project over 300 people are employed and two service provider agencies are trainers for the project. In FY2001, the curriculum was selected for inclusion in the Department of Human Services, Office of Developmental Disabilities Training Program. It is included as one component of the Qualified Mental Retardation Professionals (QMRP) training series.

In Maryland, the Council, the Division of Rehabilitation Services (DORS), and the Developmental Disabilities Administration are collaborating to provide a new employment option for individuals with cognitive disabilities who need supports in order to operate a small business. A pilot project is enhancing the DORS RISE Program (Reach Independence through Self-Employment) to provide assistance to individuals with disabilities pursuing self-employment. RISE provides exploratory seminars, business plan development course, and individual consultation.

The Pennsylvania Council Home Ownership Coordination Project, via conferences, training, newsletters & website, continues its outreach and education to individuals and organizations statewide about home ownership. They now support 20 affiliate agencies, representing 49 counties, and provide technical assistance to access available resources to finance, design, and modify decent affordable housing. Through this effort, 112 people have homes of their own, and 1890 self-advocates, family members, and others were trained in housing systems advocacy.

The above examples illustrate the importance of the Councils' responsibility of interagency collaboration and coordination and the vital role Councils play in achieving statewide service delivery goals that may be affected by downward economic trends. For more information on SCDD programs contact Mary Beth Greene at mgreene@acf.hhs.gov

Protection and Advocacy

Contract Activities

The Administration on Developmental Disabilities (ADD) exercised the option year on the T/TA contract with NAPAS. Option Year 1 covers the period October 1, 2002 through September 30, 2003. The scope of work remains the same with no additions. NAPAS staff are planning their training and technical assistance activities around crosscutting issues that affect PADD, PAIMI and PAIR. Since many of you are now organized around the areas of emphasis such as; housing, legal, quality assurance, education, health, and others, it seems to be an advantageous approach for all of us. One of the new initiatives, criminal justice to include work with prisons and jails, appears to be gaining momentum nationwide as a priority. We applaud you and the TASC/NAPAS staff in building collaborative efforts with the Department of Justice and holding a specialty meeting that was well-attended.

Face-to-Face Meetings

ADD is looking forward to the annual face-to-face meetings of the subcommittees that provide advice to TASC/NAPAS under the contract. The meetings are held in Washington, DC to allow for participation by your Federal partners. The dates are as follows: TA/QA subcommittee, October 17-18, 2002; Training subcommittee, October 31-November 1, 2002; Legal subcommittee, November 14-15, 2002; Multicultural subcommittee, December 4-5, 2002; Information/Referral subcommittee, January 7-8, 2003, San Diego, California. The Program Advisory Committee and the Information/Referral subcommittee will meet in conjunction with the Winter Conference in San Diego. These committees will now be organized around expertise and there will be no overlapping of States representation on these committees.

Best Practice

The Utah P&A just bought a new building along with other Legal service agencies in the State. This expanded resource will provide Utah constituents with developmental and other disabilities a one-stop shop for their needs and services.

Contact Jacqueline Ezzell for more information on Protection and Advocacy Agencies, jezzell@acf.hhs.gov

Projects of National Significance

A Request for Proposals (RFP) was issued in the Federal Register on May 30, 2002 for this year's PNS competition. Over the course of this year, (and following years, depending on the duration of the project) expect to see progress the five selected priority areas:

1. Learning through Assisting – a priority to create opportunities for and provide support to high school students to earn service learning credits by assisting children with developmental disabilities in inclusive environments.
2. Creating and Celebrating One Community for All Citizens – a priority to build and support local communities of diverse citizens where individuals with developmental disabilities feel welcome and able to make contributions.
3. Enhancing Early Literacy and Education for Children with Developmental Disabilities – a priority to identify evaluate and promote “promising practices” in inclusive early literacy and educational programs for young children with disabilities.
4. Increasing Access in Rural Communities with Individuals who have Developmental Disabilities – a priority to identify, develop, and promote inclusive transportation opportunities and coalitions in rural communities with individuals who experience developmental disabilities.
5. Expanding positive Youth Development Activities for Young People with Disabilities – priority to provide expanded and supportive youth development and community college experiences for young adults with developmental disabilities.

PNS had already had success with projects in these areas. For example, under priority area 4 ADD anticipates successful projects engaging in the following types of activities to achieve desired outcomes in system change and transportation services:

- Identifying and evaluating a diverse sample of promising programs and best practices in providing inclusive transportation in rural communities;
- Organizing and hosting a National Summit on transportation for individuals with DD residing in rural communities;
- Designing and offering web-based, user-friendly materials and information on transportation services for individuals with DD in rural communities;
- Identifying funding resources and opportunities for the development of and on-going costs associated with delivering inclusive transportation services in rural communities;

- Collecting and compiling data on transportation in rural areas for individuals with DD and how it effects their productivity, independence, and inclusion, as well as the local economy, their community, family, and the State's health care and services;
- Providing technical assistance to rural communities on how to develop and/or expand

model programs for delivering inclusive transportation services; and

- Promoting and establishing partnerships between consumer/parent advocacy organizations, transportation providers, disability-related groups, public/private entities, other groups serving populations who experience transportation barriers, (elderly, people living in poverty, migrant workers), and others to improve access to transportation for individuals with developmental disabilities in rural communities.

Grant awards notices have been issued to the organizations and agencies listed below for Priority Area #4. Further information about these projects and the other Priority Areas is available on ADD's web site.

1. "Project Rural Transportation Access Network" -Institute on Disability, University of New Hampshire
2. "Coalitions for a Comprehensive Transportation System" - Lee County Community Development Corporation, Inc. of Arkansas
3. "CARS: Collaborative Automobile Resource Services" - Lifestyles, Inc. of North Carolina
4. "Project Increasing Access in Rural Communities" - Montana Department of Public Health and Human and Services
5. "Creation of a Rural Transportation Network in Rural North Missouri" - City of Kirksville, Missouri with Kirk-Tran
6. "Inclusion Driver Communities" - University of Southern Mississippi
7. "NW Wisconsin Rural Transportation" - Wisconsin Coalition for Advocacy
8. "Great Plains Rural Initiative on Transportation (GRIT)" - North Dakota Center for Persons with Disabilities, Minot State University
9. "The Rural Transportation Coalition Initiative" - Massachusetts Rehabilitation Commission
10. "You Can Get There From Here National Summit on Transportation" - Indiana Governor's Planning Council for People with Disabilities

For questions relating to Projects of National Significance, contact April Myers, amyers@acf.hhs.gov.

Policy Corner

Status: Continuing Resolution

The U.S. Department of Health and Human Services, and therefore the ADD, is operating on a continuing resolution (CR), and is awaiting the passing of the FY 2003 appropriations. We will provide an "Update" in the next issue. The current CR is in effect until November 22, 2002.

Government Performance and Results Act- GPRA

The DD Network now has several years of experience with reporting on targets and outcomes under the Government Performance and Results Act (GPRA). Our program's success with

this reporting has been variable, but we are endeavoring to pursue activities to improve the accuracy of targets and the stability from year to year of our outcome data.

Currently, the outcome measures that our programs report to Congress are:

- o achieve the targeted number of adults with developmental disabilities who obtain integrated jobs as a result of DD program intervention.

[Provided by State Councils (targets in their State Plans, outcomes in their PPRs)]

- o achieve the targeted number of people with developmental disabilities owning or renting their own homes as a result of DD program intervention.

[Provided by State Councils (targets in their State Plans, outcomes in their PPRs)]

- o increase the number of health care providers trained to meet the health needs of people with developmental disabilities as a result of DD program intervention.

[Provided by UCEDDs]

- o achieve the targeted number of persons with developmental disabilities living in the community served by the P&A whose complaint of abuse, neglect, discrimination of their rights was remedied by the P&A [Provided by P&A systems (targets in their Statement of Goals and Priorities, outcomes in their PPRs)]

The Office of Management and Budget has questioned the quality of the data we collect. We can all expect a higher level of attention at the federal level on the subject of these GPRA data. Principal executives at every level in the Department are getting focussed on the importance of quality in these target and performance data. A similar level of interest in outcome measurement has also been occurring in the private sector.

Consequently, we have been focussing ADD resources on working with you to build the highest quality of data reporting that we can. Dr. Joseph Grubbs, who has had academic experience with outcome measurement, has now joined the Federal effort, and has made several presentations at national meetings this year. It may be possible for him to provide technical assistance to individual programs in the States if requested to improve the quality of their approaches to projecting targets and collecting data on actual performance.

This year ADD contributed to the Department's Annual Performance Plan to Congress, which featured outcome targets out to fiscal year 2004 (where it was available), and actual performance for fiscal year 2001. We recently received modifications to Council State Plans, which modified targets out to 2006, and we anticipate receiving Council PPRs with data on actual performance for fiscal year 2002. Similarly, we will be receiving at the end of the calendar year from P&A systems the Statement of Goals and Priorities, with target data for fiscal year 2003, and the PPRs, with data for actual performance for fiscal year 2002. ADD, and other levels of the federal government will be looking closely at this data for evidence of quality. The ADD contact for matters concerning GPRA is Jocelin Gridley, jgridley@acf.hhs.gov

Program Performance

State Councils on Developmental Disabilities

The Massachusetts Council, in partnership with The Center for Health Policy and Research at UMass Medical Center, has established the Massachusetts Federal Employment Grants Network, a collaboration of public and private agencies implementing Federal and state grant projects targeting employment, transportation, benefits, and health care for people with disabilities. The first network meeting focussed on educating participants about the objectives and activities of related projects and exploring opportunities for collaboration. Initial outcomes included developing a list serve and forming an ongoing Grants Coordinating Committee. For more information contact Wayne Perry (617) 727-6374.

University Centers for Excellence in Developmental Disabilities

Recent UCEDD activities and ongoing projects will continue to be important in FY03. The examples below emphasize the long-term effect of UCEDD programs.

The **Massachusetts** Institute for Community Inclusion at the University of Massachusetts/Boston and Children's Hospital Boston has launched a new website, www.onestops.info. This UCEDD, the National Center on Workforce and Disability, funded by the U.S. Department of Labor, provides technical assistance to one-stop career centers to build capacity to serve individuals with disabilities who are seeking employment.

The **Vermont** Center on Disability and Community Inclusion, which hosts the training component for Vermont's Family Support grant, the Green Mountain Family Network, participated in the creation of three regional interdisciplinary teams supporting parents with disabilities. Building support for parents with disabilities is a shared goal with Vermont's Protection and Advocacy Agency and Developmental Disabilities Planning Council.

Other UCEDDs have developed similar projects. **Colorado's** Parent Support Program developed an interactive computer link for parents and other adults with disabilities. The **Georgia** UCEDD worked with the Developmental Disabilities Council on a pilot program for TANF recipients who are parents with mental retardation. **Maryland's** UCEDD Growing Together project provides parenting education for parents with cognitive disabilities and has a curriculum guide, *Building Foundations*. At its Early Infant Transition Center intensive parent training is provided for parents with special needs whose children who have been exposed to drugs.

As part of a plan for family reunification the **New York (Westchester)** UCEDD offers parenting skills training for parents whose children have been placed in foster care. The **Oklahoma** UCEDD's Keeping Families Together Project also serves families in which a parent has a disability. The **Washington** UCEDD's Homebuilders Program provides crisis intervention for parents with cognitive disabilities at risk for having their children removed from their homes. The UCEDD in **Wisconsin** provides technical assistance to Human Service agencies regarding families headed by a person with developmental disabilities. The goal is to increase parent confidence and enable parents to keep their children.

In the **Tennessee** UCEDD Supported Parenting Program, graduate social work trainees serve as parent aides. Child Abuse Prevention Services funds have been used to offer a program to parents with mental retardation who have custody of their children. The **South Dakota** UCEDD held a Parents with Special Needs Conference. The **North Dakota** UCEDD participated in a pilot project of the Minot Infant Development Program to provide support services to parents with developmental disabilities. And the **Connecticut** UCEDD Parent Assessments Support Unit offers students training regarding parents with mental retardation and developmental disabilities.

For information on University Centers for Excellence in Developmental Disabilities contact Adele Gorelick, agorelick@acf.hhs.gov.

Electronic Data Submission (EDS)

Forms for FY 2002 Reports

The Program Performance Report forms for FY 2002 and Statement of Goals and Priorities (SGP) for FY 2003 are available now at ADD's Extranet Site <https://extranet.acf.dhhs.gov>. The restricted access site is used by existing customers of the Administration for Children and Families to electronically file applications and reports. For more information on EDS contact Syed Rafiuddin at srafiuddin@acf.hhs.gov

The forms are available under the headings of:

1. DDC Program Performance Report (FY2002)
2. P &A Program Performance Report (FY 2002)
3. Statement of Goals and Priorities

Five Year State Plans

The locked-in FY 2003 modified state plans are now available for viewing. The plans are located at ADD's extranet site, under "Historical Forms."

Upcoming Events & Announcements

Commissioner's Travel

CDDC/NADDC Conference, November 19, 2002, Point Clear, Alabama

Coming Soon

Publications

Protection and Advocacy Agencies 2001 Outcomes and Highlights

ADD Brochure

University Centers for Excellence in Developmental Disabilities Highlights

ADDED Resources

DisabilityInfo.gov

[HTTP://WWW.DISABILITYINFO.GOV/](http://www.disabilityinfo.gov/) A new website for Disability Resources was launched on October 15, 2002. The new site was created to centralize Government information on disability, and is part of the President's New Freedom Initiative. The new site is still in development, (and some browser compatibility kinks are being worked out) so keep checking for new information and a streamlined presentation.

Disaster Preparedness Links and Publications

ADD created a new page of links to resources on disaster preparedness for individuals with developmental disabilities in mind. The new link is available from ADD's main page, or follow this link: <http://www.acf.dhhs.gov/programs/add/dispub.htm>

State Profiles

ADD is preparing the State Developmental Disabilities Network Profiles for the ADD's Web site. Profiles will be produced with help and input from ADD Grantees. The first section of the Profile will contain the DD Network collaborative efforts/projects (as provided by the grantees) and be followed by the individual page for each DD Program in the state.

The Program page will have five sections;

1. Program Contact Information,
2. Area of Emphasis the Program focuses on,
3. Major Activities and number of persons assisted (from the latest PPR),
4. Project & Outcomes, and
5. Best Practices

These profiles will help DD Network to highlight their efforts/projects/best practices and provide information to citizens about different programs in a state.

Changes

ADD Update Delivery

This will be the last ADD Update available by direct e-mail delivery. In the future, readers may download ADD UPDATE, from ADD's Website at:

<http://www.acf.dhhs.gov/programs/add/addupdate.htm>

ADD will notify readers when each new "Update" becomes available. Readers who wish to have receive a Word Document or PDF document of "Update" may contact Nichole Dulin at ndulin@acf.hhs.gov

Farewell

ADD wishes Raymond Sanchez and Leola Brooks good luck in their new positions at the Social Security Administration!